ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

JANUARY 1992

Fort Worth Thanksgiving For Life

The Rev. Brenda Hunt was attending a Church Leadership Seminar when she was struck with the idea for a Thanksgiving for Life Ceremony, that would target the entire Fort Worth community, and draw together the people and the resources available in the city. Rev. Hunt sent out a letter in July to "every organization in Tarrant County with a Gay or Lesbian in it, or any organization remotely connected, to come together on World AIDS Day, December 1, bringing the names of loved ones who have died, and giving thanks for life."

The Thanksgiving for Life Ceremony was held during the regular Sunday morning worship service of MCC Fort Worth on the First Sunday in Advent. This Sunday, 196 people crowded into the church, including Rev. Elder Don Eastman, and South Central District Coordinator, Clarke Friesen.

The tone was set during the Call to Worship, when four panels with 48 names were brought forward and hung at the front on the two side walls of the sanctuary. The four panels were made up of smaller panels, some handstitched or embroidered in old English script, some with wood or metal plates, and some handwritten. Each individual panel represented a person who had died, not necessarily from AIDS.

Ms. Jane Rogers, AIDS Information Coordinator of the South Central District, was the preacher. Her message was "positive and upbeat." She spoke from her own experience about what AIDS has taught us all, citing the example of the many birth families who have come to know (and some who have joined) MCC's while caring for a loved one dying from AIDS.

She suggested that the Advent scriptures are very appropriate for World AIDS Day, because we are "a people of the advent, a people of renewal." Facing AIDS, "we are called to renew ourselves time and time again, always looking to new life, even at death." Rogers stated that "we have to go on. We continue. There are more to take care of." Being a people of the advent empowers us to continue with a future focus.

Ms. Rogers recalled the final scene from "Longtime Companion," where all the friends who have died appear on a pier at the beach, and then fade away. "Our faith says this really happens, but the friends don't fade. The guys we envision on the pier are still here."

The service was reported to be "up, moving, dynamic, positive, and a wonderful experience." Everyone wept, and grief was very much a part of the service. But Rev. Hunt reports that in this service, "it was the very best of grief come to life." She reports that since the service, there has been "a whole different sense, of being surrounded by a cloud of witnesses, which began with the Call to Worship and the bringing of the names."

This church has been hit hard by AIDS. There are currently 22 persons with AIDS that the pastor knows about in the congregation. She estimates that of her 140 members, there are easily 30 more HIV+ people who have not identified themselves yet. Rev. Hunt and Rev. Lew Broyles do regular AIDS Chaplaincy work at the John Peter Smith County Hospital, and this brings even more people with AIDS to church.

People from MCC Fort Worth have opened the local Names Project Chapter. They are very proud of their lavender house with the gingerbread trim, donated for use of the chapter. This is an MCC where the Body of Christ is living and thriving with AIDS, and where "the very best of grief comes to life." ▼

Task Force on UFMCC AIDS Ministry Appointed

Strategic planning for effective UFMCC HIV/AIDS ministry will be the goal of a new process initiated by the Board of Elders and approved by action of the General Council in its October 1991 meeting. The *Long Range Planning Task Force on UFMCC AIDS Ministry* has been created to conduct a needs assessment and evaluation of present UFMCC AIDS Ministry program objectives and activities. Following evaluation of the present program, this group will develop recommendations for future UFMCC AIDS ministry program objectives.

Seven members plus a chairperson and staff have been appointed by the Board of Elders to the AIDS ministry planning Task Force. Members are: Dr. Lori Dick, Los Angeles, CA, a physician; Mr. Ralph Masek, Santa Ana, CA, a marketing specialist and person living with HIV/AIDS; Rev. Jim Mitulski, San Francisco, CA, Pastor of MCC San Francisco; Ms. Jane Rogers, New Orleans, LA, AIDS Information Coordinator of the South Central District; Mr. Jorge Sosa, Mexico City, DF, Pastoral Leader of ICM Reconciliation; Rev. Paul Tucker, Dallas, TX, Director of Pastoral Care and Discipleship, MCC Dallas; and Mr. Larry Young, Dayton, OH, lay leader and former member of the UFMCC Department of People of Color's Executive Committee.

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Upcoming Legislative Issues in the U.S.

The AIDS National Interfaith Network (ANIN) continues to represent its member churches and organizations, which include the UFMCC and a number of local MCC's, on Capitol Hill in Washington, D.C. The Rev. Ken South, Executive Director of ANIN, is one of very few lobbyists in the U.S. capitol whose full-time job involves HIV/AIDS.

South anticipates five major legislative issues regarding HIV/AIDS in 1992.

✣ Appropriations will continue to be a major advocacy area. Reappropriations for standard National Institutes of Health HIV Research, as well as for the Center for Disease Control Education and Prevention programs have already been cut. The CDC, in turn, cut their grant to Black and White Men Together by 40%.

The entire Federal Budget on HIV/AIDS has increased only $100 million over last year, and $50 million of that has been targeted for the AIDS Housing Bill. So all other budget items have to split the remaining $50 million. With the ever-increasing numbers of persons diagnosed with HIV, the budget does not begin to meet the need. The Ryan White Bill will not receive nearly the full funding it needs.

South says the effort must be "to hold the line, and not let the problem slip any further."

✣ The change of the definition of "AIDS" has tremendous implications on Capitol Hill. When AIDS is defined not by specific Opportunistic Infections, but by blood counts, there will be a huge inflation in the numbers of people diagnosed with AIDS. Bills such as the Ryan White Bill and the AIDS Housing Bill will get the same amount of money, although the money will be serving significantly more people than originally projected.

✣ As a routine matter, ANIN and its member organizations will always have to do defensive legislative action. "There will always be Dannemeyer or Helms amendments on everything," South believes.

✣ South anticipates that Congressman Waxman will introduce a bill to expand Medicare's definition of AIDS, to include HIV+ persons, so that HIV+ persons will then be eligible for Medicare coverage of AZT, lab work, and other procedures and treatments.

✣ Part of the Americans with Disabilities Act goes into effect January 1, 1992, so South encourages anyone who is HIV+ or has AIDS to report any discrimination issues to the local Human Rights Commission.

South elaborated that the ADA has major implications for large religious organizations that employ over 25 people: according to the ADA, everyone will be required to make accommodations for persons with HIV. If a congregation or a denomination employing over 25 people fires someone because of being HIV+, refuses to make accommodations, or requires an HIV test, people can now sue, in some cases, for punitive damages.

Finally, South reported that the National Commission on AIDS is looking forward to much greater media exposure with Magic Johnson on board. Johnson is taking the chair left vacant by the death of Belinda Mason, who was appointed to represent grass roots people with AIDS. The Commission will go out of business in September. South encourages everyone to pressure the Commission to bring out reports on its hearings on Religion and Minority issues. These hearings were held after their official report went to press. ▼

ANIN In 1992

The AIDS National Interfaith Network (ANIN) begins 1992 entering into a contractual relationship with the National Congress of Black Churches to do AIDS advocacy and education. As a joint effort of ANIN and the National Congress of Black Churches, 100 Black clergypersons will be identified as regional aids consultants to facilitate the process of targeting 1,000 congregations in a year for AIDS education. This is a major opportunity for HIV prevention; the National Congress of Black Churches represents the six historic Black denominations, comprising over 65,000 congregations in the U.S.

Five federal programs provide funding for housing for persons with AIDS, and there is no agency monitoring that process. ANIN is currently looking for funding to act as an advocate on AIDS housing issues.

ANIN will once again be a cosponsor of the National Skills Building Conference, a very practical, and successful conference held around Halloween in Los Angeles. In 1992, the Conference will be held Columbus Day Weekend in Washington, D.C., in conjunction with the showing of the Quilt.

ANIN is also anticipating a great deal of activity around the publication, distribution, and use of the book, *AIDS and Your Religious Community: A Hands-On Guide For Local Programs* ($12.95, paperback, available through the UUA Bookstore, 25 Beacon Street, Boston MA 02108-2800, 617/742-2100). The book is a joint project of ANIN and the Unitarian Universalist Association and has already drawn rave reviews from religious leaders of many faiths.

ANIN continues to serve as an excellent network and communications agency for any congregation or religious organization concerned with HIV/AIDS. ANIN is an important lobbying voice on Capitol Hill. Through ANIN, we can be confident of having an effective lobbying presence in Washington, D.C.

Rev. South commends UFMCC for "taking the lead" in faithfulness to ANIN. Both as a denomination, and through many local churches, ANIN depends on UFMCC's support and participation.

Any religious organization wishing to join or renew their membership is reminded that the dues are only $100 for regional or local membership. Write to ANIN at 300 "I" Street, NE, Suite 400, Washington, DC 20002; or call ANIN at (202) 546-0807 for more information. ▼

{Task Force...continued from pg 1}

Rev. Elder Don Eastman will serve as chairperson and Rev. A. Stephen Pieters, Field Director of UFMCC AIDS Ministry will serve as staff of the Task Force.

The Task Force will begin work with a meeting in Los Angeles in April 1992, and complete its process with program recommendations submitted to General Council in March 1993, for incorporation into Program and Budget approved by the 1993 UFMCC General Conference. ▼

U.S. National Lesbian and Gay Health Conference Scheduled

The 14th National Lesbian and Gay Health Conference and the 10th Annual AIDS/HIV Forum will be held July 8-12, 1992 at the Los Angeles Airport Hilton and Towers, Los Angeles, CA. The Conference is cosponsored by The National Lesbian and Gay Health Foundation and The George Washington University Medical Center.

The theme of the conference is, "Making Health Care Human: The Impact of Age, Gender and Race" with a special educations track on "Strategies for Inclusion - Responding to the Changing Face of AIDS."

The conference is preceded by full day "intensive and in-depth institutes" in such areas as Gay and Lesbian Youth, S/M, People of Color, Domestic Violence, Lesbian Health, Caregiver Burnout, Sexual Abuse, Anti-Gay Violence, Incarcerated Populations, and Spirituality.

The conference will feature plenary sessions with nationally known figures speaking on a wide variety of issues important to the Lesbian and Gay community. Concurrent sessions will be presented in five educational tracks: AIDS/HIV Forum, Lesbian and Gay Health, Mental Health, Substance Abuse, and Strategies for Inclusion.

UFMCC has made important contributions to past conferences. Last year, Rev. Elder Troy Perry led the Spirituality Institute, which featured Rev. Shelley Hamilton and Rev. Steve Pieters. Many people from MCC's have found the conference to be an invaluable opportunity to build skills and to network.

A preliminary program with conference registration forms and information will be available after April 1, 1992. To receive the program with registration materials, write to:

NLGHF Registration
c/o The George Washington University
Medical Center
Office of Continuing Medical Education
2300 "K" Street, N.W.
Washington, D.C. 20037 ▼

566C80 Expanded Access

Activists succeeded in pressuring Burroughs Wellcome to develop an expanded access program for 566C80, a promising treatment for PCP and toxoplasmosis. Burroughs submitted an application for the access program to the FDA, with hopes that approval would be granted in mid-October. The FDA has finally completed its review (a month later) after several inexcusable delays, and approved a 566C80 expanded access program.

To enroll, individuals must have PCP and a history of dose-limiting intolerance to TMP/SMX (Bactrim) or an inadequate response to TMP/SMX. Physicians should call 1-800-755-2020 to register patients. ▼

Underground Buyer's Club

The following is a list of the eight largest buyers' clubs in the country. Many underground groups, both unapproved and approved abroad, carry nutritional supplements and vitamins, as well as minerals, enzymes and herbal or Chinese therapies. It is important to ask questions and explore the standards and procedures of any group offering unapproved therapies before buying a drug from them. Also remember to consult with your doctor.

*Alliance 7 Buyers' Club
San Diego, CA
(619) 281-5360

*AIDS Action Baltimore
Baltimore, MD
(301) 837-2437

*Carl Vogel Foundation
Washington, DC
(202) 289-4898

*Dallas Buyers' Club
Dallas, TX
(214) 826-7455

*DC Buyers' Club
Washington, DC
(202) 232-5494

*Healing Alternatives Fdtn.
San Francisco, CA
(415) 626-2316

*Los Angeles Buyers' Club
Los Angeles, CA
(213) 748-1295

*PACT Buyers' Club
Tucson, AZ
(602) 322-9808

*PWA Health Alliance
Oakland Park, FL
(305) 568-3001

*PWA Health Group
New York, NY
(212) 532-0280

Clarithromycin & Azithromycin Approved

{reprinted with permission from Treatment Issues, Vol 5, #9}

Two antibiotics, clarithromycin and azithromycin, which are promising prospects for the treatment of HIV-related MAC and toxoplasmosis, have at last been FDA-approved. Azithromycin (brand name Zithromax), made by Pfizer, is now licensed as treatment for certain respiratory and skin infections and for chlamydia. Clarithromycian (brand name Biaxin), made by Abbott Labs, is approved for upper and lower respiratory infections, as well as uncomplicated skin infections.

The good news is that the drugs will become more available for use in HIV-infection. The bad news is that they are expensive, and when used for non-licensed conditions, such as HIV-related MAC or toxo, ("off-label use") the cost of the drugs may not be reimbursed by third-party insurance or Medicaid/Medicare. ▼

ALERT

ALERT is a monthly newsletter containing information on AIDS Legislation, Education, Research and Treatment. The Editor is Rev. A. Stephen Pieters. For more information, please write: ALERT, c/o UFMCC, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029.

Update On Peptide T

{reprinted from Treatment Issues, Vol 5, #8}

Peptide T was invented as a potential AIDS therapy in 1986 by a group of scientists, including Dr. Candace Pert at the NIMH. The drug is a string of eight amino acids configured to prevent HIV from attaching to and thus infecting cells. Cells that have already been infected by HIV, prior to therapy with Peptide T, will remain infected until the cell dies. The body, however, less vulnerable to HIV, should have a dramatically enhanced ability to ward off the effects of the virus. In addition to this, Peptide T is a neuronal stimulant which is potentially therapeutic for people with HIV/AIDS. Several phase I clinical trials for Peptide T have shown the drug to be non-toxic. Phase I trials suggest that Peptide T stabilizes T4-cell counts and improves HIV-related diarrhea, dermatitis, and neuro-cognitive disorders, such as memory or concentration loss, fatigue, and depression.

Update from Florence

Results from a federally-funded, double-blind, placebo-controlled trial of Peptide T were reported at the international conference in Florence by Dr. Peter Bridge and others. Evaluations of improvement were based on neuro-psychologic tests. No toxicity was observed, and the greatest improvement in neuropsychologic function and symptom report was seen in patients taking the lowest dose of intranasal drug; that is, 1.2 mg/day.

Another study by Dr. McFadden and others from Canada found that injected Peptide T is an effective, non-toxic, pain reliever for HIV-related peripheral neuropathy.

Finally news from Florence evidenced that Peptide T given intravenously, helps nerve cells survive, according to results of 15 AIDS and ARC patients receiving the drug.

Availability of Drug

Peptide T is available through two clinical trials: one in Los Angeles for intranasal use, and one in Connecticut for people on methadone and AZT. Additionally, the drug can be bought through buyers' clubs. At the L.A. Buyer's club, the cost of Peptide T at 50 ml is $200.00, a supply that lasts about 40 days at 6 mg/day. (Prices may fluctuate). For more information call (213) 748-1143. The PWA Health Group in New York has also recently received the drug. The cost is $95.00 per 125 mg, a supply which lasts about 21.8 days. For more information call (212) 532-0820. ▼

An Open Letter to Magic Johnson

Editor's Note: The following is an anonymous open letter printed orginally in "The Channel" of St. John The Apostle MCC in Ft. Myers, Florida.

Dear Earvin "Magic" Johnson,

I am not a sports fan, so I've only seen you in shoe commercials; and yet, I want you to feel my support and admiration. In the Book of John, when they encountered a man who was born blind, the Apostles asked Jesus, "Why was the man born blind - to punish him for the sins he was going to commit, or to punish the parents for their sins?" Jesus answered that he was born blind not to punish any sins but so that God could be glorified in his healing.

I have HIV infection, and, like you, I did not get it through my dentist, doctor, a blood transfusion or any of the means that would qualify me as what some folks call "an innocent victim." In fact, I struggle to banish the word "victim" from my mind. HIV is not God's punishment for my sins, yours, or anybody's sins. I like to think of HIV as a catalyst; and like the man born blind, all I know is that I now see things I didn't see before.

I have come to believe that we who are infected must confront our mortality and therefore go through the grieving process for ourselves. This is not so that we become passive fatalists who are content to wait for death's knock at the door. I believe, rather, that to meet the challenges and opportunities of our condition, we need to "get right" at the center of our being.

The stages of grief cannot be forced, yet understanding the process can lend guidance to the journey. The first stage (I say "first" although the stages don't follow a sequence. A person can move backwards, get stalled or be in two stages simultaneously), is denial or disbelief. When faced with the loss of a loved one, this stage is characterized by shock, and often only lasts a few days at most. When faced with our own looming demise, denial can be insidious and persistent. It may disguise itself as a positive outlook and meld with the bargaining stage: "I'm not going to die; I don't abuse drugs; I live a healthy lifestyle and take good care of myself; and besides, I have a positive attitude." There is nothing wrong with that outlook except that if it comes from denial or bargaining, then the anger stage has not been worked through. Anger can short circuit our positive, healing drives. I know, in my anger I want to point blame outside of myself. Sometimes I point at myself, but for as long as I blame, I not only deposit guilt with someone (me, God, "them"), I also paint myself as the object of some wrong doing and tie up my energy and outlook by feeling helpless and victimized. The sense of being a victim, strangely, has an appeal: "I can let others take responsibility for me and take care of me!" Each setback in my health forms an opportunity to receive this care. I am helped out of this trap by examining my anger: Who do I blame? Those promiscuous gays? Those irresponsible drug abusers? My parents for not teaching me sufficient self esteem? God? Myself? These are not pretty feelings; but, ifI have them, I need to take them out, hold them, feel them and look at them. A support group, or a friend to confide in, or the twelve steps of Alcoholics Anonymous can help. By coming to see the futility of my anger and realizing that I can choose to forgive whoever for whatever, I am freed. The move into the final stage, acceptance or forgiveness, comes with some pain, perhaps tears, and a sweet and sad feeling beyond sentimentality-a stark sense of the presence of God, of eternity now. It is the feeling of peace "beyond understanding" that I wish for you. You may need to ask, "God, why me?" That qestion comes from all the prophets, David in the Psalms, and Jesus. I believe that God has chosen you, Earvin "Magic" Johnson, to lift up this disease and all of us who are affected by it. I don't know why, still I pray that you'll have the faith to be filled by God with courage, strength, love and hope, and that you'll feel God working in your life. ▼